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Title: Bridging the Gap: A qualitative study exploring the value of a Catheter Passport

Background

Living with a catheter can have a profound impact on a person's physical, psychological and social functioning (Darbyshire et al, 2016; Wilde, 2002). In the UK, around 450,000 people use long-term urinary catheters (Prinjha & Chapple, 2013). As there is no clear protocol for discharging patients from hospital with catheters some patients leave hospital without knowing why they have a urethral catheter in situ, or how to self-care with it. This has been attributed to insufficient information, a passive attitude towards catheters by health professionals and the care culture of the ward, or hospital (McNulty et al., 2008; Dingwall & McLafferty, 2006). Inadequate support on discharge from hospital means that patient's physical and practical needs are often unmet. In addition psychological support for patients who may experience difficulty adjusting to altered body image and sexual expression is not adequately addressed (Prinjha & Chapple, 2013; Fowler et al., 2014; Godfrey, 2008; Kralik et al, 2007; Wilde, 2003 & 2015; Sweeney et al, 2007).

Community nursing teams and GPs often receive patients leaving hospital without a clear rationale for their catheter. Locally, 37% of catheterised patients had no mention of the catheter on their Discharge Summary (Royal United Hospital, 2014). This communication gap means that healthcare staff don't have the "*full story of the catheter journey*" when people with catheters access a range of cross-sector services (Dean, 2016 p21).

These problems disempower both patients and staff. NHS England (2015) and the Royal College of Nursing (2012) advise that providing patient information on discharge is essential to ensure safe, high quality care for patients. Dangers of infections associated with catheters are well reported and catheter-associated urinary tract infections (CAUTIs) can result in

extended and costly re-admission to hospital care (Loveday et al., 2014; Tenke, 2008; Smyth, 2008). NICE (2014) and Loveday et al (2014) advise that catheter-users should be educated about safe catheter management, including techniques to reduce infections.

One strategy to address the dual needs of patients and healthcare staff is to provide a patient-held document, with information and a record of catheter care.

A team of nurses and patients at one NHS Foundation Trust co-created a catheter passport, which was trialled over an 8-week period (Box 1). A small number of catheter passports already exist within NHS Trusts (Buckley et al., 2015; Codd, 2014; Dean, 2016; Ford, 2015). However, no published research investigating their efficacy has been identified. This paper reports on research conducted to explore the experiences of patients and nursing staff who trialled the co-created passport.

Aim

The research aimed to explore how a patient-held catheter passport affects the experiences of patients leaving hospital with a urethral catheter, the hospital nurses who discharge them and community nurses who provide ongoing care to them.

Methods

A qualitative study was designed to understand the experiences of patients and nurses using the catheter passport. Thematic analysis was chosen as a flexible research tool, which can provide both a descriptive and interpretive account of the data (Clarke et al 2015). Data were collected via structured interviews, questionnaires and focus groups, between January and March 2016. Approval for the study was granted by the local NHS Research Ethics Committee.

Participants

Eligible patients were aged over 18 and had been discharged with a urinary catheter from specified wards at one hospital over 8 weeks. Eligible registered nurses worked on specified wards at the hospital or within the CCG and had come into contact with at least one patient with a catheter passport. In total 9 patients, 6 hospital nurses and 5 community nurses participated in interviews and focus groups, with 38 nurses completing a questionnaire.

Sampling, recruitment and data collection

Patients: A purposeful sampling strategy was used to recruit patients who met the inclusion criteria. Ten patients were recruited and were telephoned 2-4 weeks after their discharge to ask if they had used the catheter passport. Nine responded affirmatively (8 men and 1 woman) and all took part in face-to-face interviews at the urology outpatient clinic, or in their own homes. Due to the sensitive nature of the topic two research nurses conducted the interviews, using a structured interview schedule, with open and closed questions. The catheter passport was used throughout the interview, to stimulate discussion. Eight of the patient interviews were audio recorded and transcribed and one (where the participant declined to be audio recorded) was captured by detailed notes.

Nurses: Focus groups were conducted with nurses. Four nurses attended the community nurse focus group, representing district nursing, the nursing home sector and community rehabilitation hospital nursing. One, unable to attend the focus group, was interviewed afterwards. Six acute hospital nurses attended the second focus group, representing both surgical and medical wards. The focus groups were facilitated by the research nurses and a qualitative researcher. They were audio recorded and transcribed. A questionnaire including closed and open questions was completed by 33 hospital nurses from four wards (2 surgical

and 2 medical). Five questionnaires were completed by community nurses. The questionnaire and interview guide were developed in collaboration with patients and nurses.

Analysis

The qualitative data, including interviews, focus groups and free text from questionnaires, were analysed using Thematic Analysis (Clarke et al 2015). The data for each of the three participant groups was coded, grouped into categories, and themes were identified. This was done manually, as a collaborative process between the qualitative researcher and the research nurses, who discussed and compared codes and categories to identify and refine emerging themes.

Findings

Thematic analysis identified the following over-arching themes across the whole data set:

Informing patients, informing nurses

The catheter passport improved knowledge about and awareness of catheter care for all patient participants, providing reassurance after discharge. The passport was reportedly easy to use, with clear language and helpful photographs. Interviewees regarded it as an essential source of information and reference, and most kept it close at hand once home from hospital. Patients expressed surprise that catheter passports were not standard issue. They saw it as important for “back up” and “checking” what may be missed by busy staff;

“The nurses... have so much to do in such a small space of time and things get forgotten...That’s why the passport is good” (patient 023)

Hospital and community nurses were acutely aware of current information gaps when a patient is discharged with a catheter without supporting documentation;

“we never get that information on handover...sometimes you can’t find that information”

(community nurse ID3/FG).

They therefore regarded the catheter passport as an up to date record of a patients’ catheterisation, which could be shared across different settings;

“the information follows the patient, makes it safer for the patient – whoever is doing the catheter care” (hospital nurse ID5/FG).

Nurses identified that to be an effective care record, the passport would need to be brought with the patient and completed by staff at all admission and discharge points. They saw the passport as an opportunity to increase their knowledge and confidence in catheter care. The step-by-step guides and checklists were identified as useful reminders and prompts, particularly for nurses who infrequently discharged patients with catheters. Some nurses said the passport could improve communication with patients, prompting them to ask about sensitive or personal issues that are often missed;

“it made me think a lot about the patient and how a catheter in situ must make them feel...the passport would be very useful when questions were raised” (district nurse ID5/Q).

Improving Catheter care, Promoting self management

Knowing when and why a patient was given a catheter, when it is due to be changed and when a trial without catheter (TWOC) is planned, was identified by nurses as enabling better continuity of care, a safer discharge and better planning;

“[the passport is] a good way of communicating between community and acute settings as we often have patients unable to explain when and why their catheter was inserted” (hospital nurse). ID28/Q

Nurses agreed to improve care the passport should be embedded into practice and expressed the need for ongoing training of staff. Although completing the passport would

take extra time, this was regarded as worthwhile to reduce duplication, enable a better discharge and improve patient safety. The potential for reducing repeat admissions for catheter problems was seen as time-saving in the longer term. It was important to nurses to; *“monitor who is going home with it, be able to help the patient or relative and avoid overlooking what is needed by a patient with a catheter” (hospital nurse). ID23/Q*

Community nurses expressed that the passport would save them time by less *“trawling of the notes”* enabling them to plan home visits and to pass relevant information between settings.

Both nurse groups hoped that the catheter passport would promote patient *“ownership”* of their catheter; bringing a sense of *“control”* and *“confidence”*. Most patient participants used the passport for, *“reassurance,” “educating”* themselves about their daily routines and for managing their catheter at home;

“I had an idea how catheters worked, but no real picture in my mind...the pictures gave me a good idea of how the system all fitted together...it was a case of looking through the passport and getting on with it really” (patient 023).

“I had some knowledge of what should be done... but the Passport focussed my mind [on hygiene]” (patient 011)

Patients found the step-by-step instructions, photographs and troubleshooting pages particularly useful for themselves and family members;

“it’s a very practical approach to look at how to take the bags on and off...it was this book and photo section that was really useful” (patient 010).

Several patients used the passport proactively, finding answers for positioning and drainage options, or changing their hygiene practice after reading about infection risk. One participant acted to get rid of his leg bag after seeing valves in the passport.

However, ongoing problems that restricted daily life such as difficulties moving about, discomfort and concerns about bag capacity were described and some preferred to discuss their concerns before taking action;

“I would have appreciated someone sitting down with me and discussing it...If I had had an opportunity to speak to a district nurse right at the beginning, it would have been better” (patient 040).

Others chose to “*put up with*” practical problems such as badly fitting or incorrect supplies, because their catheter was in situ for a short time. Several patients completed the Catheter Diary section of the passport, but most felt it would be more relevant to those using a catheter for a longer period.

Supporting Transition

Patient participants commented on the excellent care they received in hospital, but both patients and nurses described the last minute “*rush*” and sometimes “*confusion*” of their discharge with a catheter. Nurses and patients agreed that a good discharge would involve time spent together, discussing and completing the catheter passport and practising routines;

“Teaching catheter care from day 1 is important, especially for older patients and people who are less confident with self-care” (District Nurse ID1/FG).

Several patient participants reported good practice at discharge, whilst others had been; “*left to get on with it*” (patient 023).

Some described difficulties with leakages and accidents that affected their confidence and caused embarrassment. Several patients who felt unwell after discharge were not in the right frame of mind for taking in new information and suggested that the catheter passport could be issued earlier;

“it would have been better to get all this [catheter passport] before the operation. I wouldn’t be under pressure or under the effects of the anaesthetic” (patient 012)

Nurses and patients were pleased to see emotional concerns and issues around intimacy addressed in the catheter passport. Although most participants said they used the passport for practicalities, they agreed it was important to address the emotional issues in the passport especially regarding self-image and confidence;

“I realised it was normal but I wasn’t prepared to suffer it [wet patches]...the most emotional thing for me is the wetness – it’s so demoralising” (patient 024).

Most patients said that a combination of information in the catheter passport and ongoing communication with a trusted nurse was important for managing the transition from hospital to home with a catheter. Those who were just handed the passport said they would have liked more help;

“I may have worked it out [with the catheter passport] but you still need that conversation with someone” (patient 021).

Several patients said they would welcome access to ongoing support from a nurse;

“Weekly catheter drop-in clinic, a walk-in clinic or on the phone, would be good to have reassurance from a real person” (patient 024).

Limitations

Whilst based on a small sample, the findings draw on in-depth data from three different groups of stakeholders and are appropriate for a qualitative design. The sample size did not allow a comparison of perspectives and experiences of short and long term catheter users, which are likely to be different (seven patient participants had been catheterised for a short period of time, whilst two were longer term users). Three patient participants who had undergone radical prostatectomy surgery had been given an information leaflet on discharge,

plus a direct line to the urology specialist nurse, as well as the catheter passport. This may have resulted in them being better informed and supported than patients who have not had this surgery.

All nurse participants had received teaching, or had read teaching materials about the passport. However, of the 38 nurses who responded to the questionnaire 10 hospital nurses had not yet issued a catheter passport at discharge. Recruitment of community nurses was challenging as it required them to contact the researchers when they cared for someone with a catheter passport. Despite subsequent efforts to directly contact nurses who were likely to have received a patient with a passport, only 5 community nurses participated.

Discussion

Whilst catheter passports have been created elsewhere, this is the first study to research the impact of an accessible and comprehensive catheter passport that was co-created by patients and nurses. This study provides insight into how a patient-held catheter passport may be used by patients and nurses and the implications of it for nursing practice.

Information and Communication tool

Nurses in this study were very conscious of the communication gap between hospital and community staff when patients leave hospital with a catheter, and could envisage how the catheter passport would improve this deficit. The passport would need to be completed at all points on the patient's journey to be an effective care record and documentation bridge for healthcare staff, and nurses were aware that it would take time to embed the catheter passport into practice. An ongoing programme of staff training alongside reinforcement and communication with patients will be required to ensure the catheter passport is used to optimum effect.

Patients in this study regarded the catheter passport as providing essential and necessary information, using it primarily for reference and reassurance about practical issues. Emphasis will be needed to ensure that patients prioritise it as a patient-held record that travels with them to all health-related appointments and hospital visits.

Improving catheter care

Guidelines exist for good quality catheter care (Loveday, 2014; NICE, 2014) but failure to meet these standards is well documented (Prinjha & Chapple, 2013). Nurses in this study were optimistic that, by providing information about the patients 'catheter journey' and improving communication with patients, the passport could lead to better self-care.

Evidence highlights how leaving hospital with inadequate information about their catheter can affect patients' psychological and social adjustment (Sweeney et al 2007). The catheter passport has an important role in promoting self-care, which is most effective if it starts in hospital with nurses doing less 'for' patients, and more 'with' them. Ongoing support is important, as patients in this study who had received support and instruction from a nurse felt prepared and confident. They appeared more likely to practice self-care than those who had just been handed the passport at discharge. While this has implications for nurses' time in the short term, the potential longer term gains of a confident and knowledgeable patient is achievable. The hospital Trust has already acted on the study findings, by rolling out the catheter passport to all patients being discharged with a catheter and offering a weekly drop-in 'Catheter Clinic' run by urology specialist nurses, where patients, carers and hospital staff can access training and support. A ward infographic has been produced to act as a quick reference guide for busy ward staff (Box 2) and discussions have started on issuing the catheter passport at pre-operative assessment clinic.

Recommendations

All patients with catheters should be provided with essential information about their catheter to enable and empower them to self-care. This should include; why they have the catheter, how to reduce their risk of developing an infection, who to contact in case of problems, catheter management and choices around drainage options. A patient-held catheter passport might be an effective way of providing this information to patients and health professionals. Healthcare Trusts should prioritise safety and quality initiatives, such as the catheter passport, to reduce unnecessary harm to patients and costs to the Trust.

Further research is needed to evaluate the impact of catheter passports over time, particularly on patient and staff concordance with maintaining it as an accurate record. Such research could provide further insights into how the catheter passport works as a documentation bridge, its impact on infection and re-admittance rates and how it is used by patients living with a catheter long term.

Conclusion

The research study has demonstrated that the catheter passport can bridge the information gap, improve care, promote self-care and help patients adjust to their catheter, especially if used alongside ongoing input from a trusted nurse or other health professional.

Key phrases:

1. Many patients leaving hospital with a catheter do not have sufficient information to self-care and experience physical and psychological difficulties
2. Healthcare staff report gaps in communication when people with catheters access a range of cross-sector services.
3. Safe, continuous care can be delivered to patients between settings by providing the patient with a completed catheter passport.

4. Patients can be empowered to self-care by providing essential information about their catheter, infection risks, drainage options and troubleshooting
5. To act as a communication bridge, patients will need to carry their passport to appointments/hospital and health professionals will need to update it at each interaction
6. Nurses will need to embed the idea of a catheter passport into their own practice as the tool is more effective when nurses spend time explaining its function to the patient.

Questions for reflection:

- 1. Reflect on the RCN Catheter Care (2012) report. If you are transferring a patient with new urinary catheter, consider what information and equipment you should provide.**
- 2. What are the benefits and dangers of empowering your patient to self-care, in your work area?**
- 3. Reflect on the phrase 'care without walls'. What methods are available in your organisation for cross-sector working and which method would you choose in order to provide patient information to a nurse outside of your organisation?**

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